



# THE 2005 DISABILITIES POLICY IN FRANCE. AN OPPORTUNITY FOR THE DEVELOPMENT OF DISABILITIES STUDIES

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## THE 2005 DISABILITIES POLICY IN FRANCE.

### AN OPPORTUNITY FOR THE DEVELOPMENT OF DISABILITIES STUDIES <sup>1</sup>

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#### ABSTRACT

*Following the European charter of fundamental rights (Treaty of Nice, December 7, 2000), the French law 2005-102 renews the institutional frame in which questions relating to disability can be tackled in France. The emphasis on citizenship and on individuals' rights put on the agenda the issue of discriminations regarding people with disabilities. The legal definition of disability as limitation of activity or restriction in participation in social life leads to direct research to the different institutional, social and cultural barriers which oppose citizenship. This institutional frame offers opportunities to develop researches referring to the social model of disability and to participate in the international debates in the field of disabilities studies by bringing into it the French social policies.*

*It also opens new directions for tertiary education on disabilities. As disabilities issues cross the economic and social sectors, the major tertiary curricula need to develop professional competencies to tackle discriminations and issues of social participation. As disabilities issues are a specific field of public intervention, the development of specialized competences is needed to implement institutional and structural conditions for the development of the citizenship and for the empowerment of disabled persons. Following disability studies, this institutional frame also put on the agenda the question of the voice of disabled people in research and education.*

*The contribution will discuss these different stakes relating to disabilities issues in the new institutional frame on disabilities in France.*

#### KEYWORDS

*Disability, disabilities studies, individual model, social model, 2005 French Law on disabilities.*

To discuss the impact of public policies on training and research on disability in France, the institutional context of disabilities policies will be shortly presented, as research and training issues are partly embedded in it. This context can be defined with reference to two laws: that of 1975 which was decisive in the organization of research on disabilities until now, and that helps explain the central place of the individual model of disability which has been dominant in the development of institutional responses to disability; that of 2005 which opens new opportunities for the development of a social model of disability. In France, the word "handicap" is commonly in use while it is deemed to be politically incorrect elsewhere. However, with its ambiguities, it is constituent of the institutional context and can therefore be used as an indigenous category, of the French disabilities policies.

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### **The individual model of disability in the 1975s law on disability**

In the 1970s, most Welfare states have developed disabilities policies. In France the law of June 30th, 1975 defines a national obligation towards handicapped persons. This law follows the Bloch-Lainé report<sup>2</sup>, a public report by a senior civil servant, on the maladjustment of disabled persons and of the public responses to their situations. The report defines a doctrine based on solidarism<sup>3</sup> to justify and organize the intervention of the State on the problems and situations identified by the report and to which no regular institutional response is provided.

The 1975 law rests on the paradigm of disability as an unpredictable misfortune, or a personal tragedy<sup>4</sup> of which consequences for the individual and its family must be compensated. The disability policy is marked by a conception of the handicapped persons as being under the protection and the care of state<sup>5</sup>. The object of this policy is made of the deficiencies or impairments of the persons which give them the possibility to claim a status of “handicap” to commissions composed of medical and social professionals. The status opens the possibility to ask for legal compensations. Disabilities policies responses are implemented on the basis of a regular and general principle of the Welfare state, but the allocation of a specific status; this explains why the definition of a national obligation is central in the integration of disabilities in the architecture of the social rights.

The 1975 law rests on an individual model of disability which is an extension of the medical model to the social realm. It is centred on the persons and on the consequences of their impairments in the access to an ordinary environment of life. These limitations contravene the principles of equality of chances and must be compensated. So, the access of disabled persons to the ordinary institutions and contexts of life and job must be made easier « *each time the aptitudes of the handicapped persons and their family makes it possible* ».

### **Implications for research and training**

The founding principles of this law and their implementation orientate research and education issues regarding disabilities towards the promotion of an individual model of disability. The central object is constituted by the condition or the attributes associated to the persons which prevent their participation in ordinary life. One develops interest on the inclusion of disabled people in ordinary life, and on the limitations to which they are confronted due to their deficiencies or impairments. In this approach, the attention is not driven to social, cultural and institutional environment in the production of disability.

This model is promoted in the training of professionals of the care to disabled, which is centred on deficiencies, impairments and their compensation or remediation. This training develops in a context of normalisation of the closed institutions, inherited from the history of the care to the different categories of paupers.

As research is concerned, the production of knowledge is predominantly focused on the handicapped persons, the possibilities of remediation and the conditions of their social integration. The social and cultural contexts of integration are not much questioned except for studies on the historical and cultural production of disability, social representations of disability or ethnographic research on mental deficiency<sup>6</sup>. In the international context, French research appears centred on the handicapped persons and not very open to debates on discrimination and

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<sup>2</sup> Bloch-Lainé F., 1967, *Etude du problème général de l'inadaptation des personnes handicapées*, Rapport présenté au Premier Ministre, Paris, La documentation française ;

<sup>3</sup> On solidarism : Rabinow P., *French modern. Norms and forms of the social environment*, Cambridge-Mass. MIT Press. ., Blais M.-C., 2007, *La solidarité. Histoire d'une idée*, Paris, NRF Gallimard.

<sup>4</sup> Oliver M., 2009, *Understanding disability. From theory to practice*, Basingstoke, Palgrave MacMillan.

<sup>5</sup> de Swaan A., 1988, *In care of the State: health care, education, and welfare in Europe and America during the modern era*, Oxford, Oxford University Press

<sup>6</sup> For an overview of French social research on disabilities : “French disability studies” , Guest editors : J.-F. Ravaut, I. Ville, *Scandinavian journal of disability research*, vol. 9, 3-4, 2007,

on empowerment. Disabled persons are not much present in the definition of orientations and in the realization of research on disability.

### **The context of the individual model**

Several reasons can be invoked to explain this focus on an individual model of disability; It rests on the predominance of a medical and psychiatric (as regards intellectual disability) approach to disability. The first developed after World War 1 to look after and to readapt the wounded soldiers and civilians of the war, and by extension after some years the impaired whereas the second was formed after the World War 2 to take care of the so-defined “maladjusted”.

The training of professionals involved in the field of disability (social workers, paramedical occupations) was centred on individuals and on responses that could be brought to them. In addition, this training aimed at the transmission of professional know-how, and was not interested in research issues.

Social scientists showed a weak interest for disability issues, in a context where under the influence of Michel Foucault, attention was turned towards institutions and their role in a normalization of populations. Although it exemplifies the bio-power and the process of normalization, disability is not conceived as a major political stake, contrary to psychiatry. It can also be asked if the translation of Goffman's *Stigma* in 1975 and its strong association with disabilities has not limited the sociological imagination in this research field<sup>7</sup>.

Finally, the role of voluntary associations of handicapped people (and of parents of disabled persons) who implemented the disability policy by managing facilities for the handicapped persons limited the possibility of critical voice of the handicapped leading to take into account the role of environment in the production of disability.

### **The critics to the 1975 law**

The law of June 30th, 1975 has been largely criticized on political grounds in the 1990s. Critics concerned particularly the attribution of the status of “handicap” that put the persons in a bureaucratic dependency and opposes their control over their own lives. The positive discrimination which this status tended to express is rejected in the name of a demand of equality of rights. There is a claim to be recognized as actors and not as subjects depending on social policies.

These critics developed in France at the time when the Charter of the fundamental rights of the European Union was under discussion and negotiation<sup>8</sup>. They leaned on this charter which established a principle of non-discrimination to claim to remove the status and to promote an approach centred on individuals and citizenship.

The conjunction of these critics and of the obligation of adaptation of European directives in national Law has resulted in the law of February 11th, 2005 « on rights and equality of chances, participation and citizenship of disabled persons ». This law constitutes the new institutional reference frame for disability policies.

### **The 2005 law and the move towards a social model of disability**

The 2005 law rests on a new paradigm of disability as a possible condition for every individual, and no as personal tragedy of some ones. “Handicap” is defined as limitations to social participation and citizenship. The object on which disabilities policy is called to intervene is constituted by the “situations of handicap” i.e. the situations which restrict participation to life in society and citizenship. The objective of the policy is to guarantee the rights of the persons in situation of disability as citizens.

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<sup>7</sup> The subtitle of “*Stigma*” in French is “*The social uses of handicaps*”, to compare to the original subtitle “*Notes on the management of a spoiled identity*”.

<sup>8</sup> Treaty of Amsterdam 1999; Treaty of Nice 2000.

Contrary to the law of 1975, the law of 2005 is not centred any more on individuals and their impairments; it considers participation in life in society as a normal situation and not a situation which depends on possibilities of the handicapped person. Moreover, law asserts the right of disabled persons to the compensation of consequences of their disabilities according to their needs and aspirations expressed in their « life project »<sup>9</sup>.

Following the Swedish model of disabilities policy, but with the peculiarities of the French bureaucratic organisation, this law rests explicitly on a social model of disability. Its objective is to assure the normal citizens rights to persons with deficiencies or impairments and to intervene on the restrictions of citizenship and participation in social life they experience. These limitations of citizenship and participation in social life are considered as discriminations.

In its formulation, which is very talkative, the 2005 law defines principles, but it is their implementation in a historical and institutional context which must be considered. In spite of a move towards a social model of disability, the law is characterized by tensions, or even mutual exclusions between the consideration of impairments of the individuals and the attention given to the limitations of citizenship. In addition, the notion of compensation remains centred on the individuals, with tensions between the consideration of the needs of persons and a bureaucratic treatment resting on general norms.

### **New opportunities for research on disabilities**

In spite, and perhaps because of its ambiguities, this institutional frame offers opportunities to develop researches referring to the social model of disability and to participate in the international debates in the field of disabilities studies, defined extensively.

Opportunities for research must be differentiated according to their objectives. On the one hand, one can consider applied research, or “involved research” to follow Norbert Elias, with objectives of implementation of the new institutional rules and of assessment of disabilities policies. This field is institutionally organized through the cooperation between voluntary associations, public administration and researchers in order to define research agendas and priorities. It benefits from extended quantitative research on disabilities that allows documenting the different demographic and social configurations and trends of disability. These quantitative studies need to be regularly conducted and followed up to improve the extent of configurations of disabilities and to provide researchers with data for specialised quantitative or qualitative studies. Among research priorities, the decentralized level of implementation of disabilities policy must hold attention, as it can generate territorial and social inequalities. In addition, the social and administrative definitions and uses of the category of “life project” must be investigated, as it is the cornerstone of the new policy. As individuals and social groups have differentiated capacities to voice and to make claims, life projects should be interesting indicators of the production of social inequalities.

On the second hand, systematic or “detached” research on the production of disability must be developed, even if it is not immediately central in public decision, as it develops a critical approach to the institutional process. Research on the implementation of the 2005s law must be sustained by extended research on the different dynamics involved in the production of disability, on ethical and human rights issues and on their contribution to social and institutional structuration. For example, the use of the notion of « life project » can be analyzed with reference to bureaucratic rituals and to reflexive biographies, and as regard ethical issues involved in the control over private life<sup>10</sup>. Such an analysis is prone to draw the attention on dimensions ignored by applied research. Research is needed to analyse, in an autonomous way, the process of production of disability and, on this basis, to examine the effects of public policies. Researchers

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<sup>9</sup> My translation of the notion of “*projet de vie*”.

<sup>10</sup> Giddens A. , 1990, *The consequences of modernity*, Stanford CA, Stanford university Press ; Beck U., Beck-Gernsheim E., 2002, *Individualization. Institutionalized individualism and its social and political consequences*, London, Sage , Theory, Culture & Society

have to be in capacity to construct their own research objects and to critically question in a the policies of disability and the practices of compensation which are implemented, as well as the barriers which oppose citizenship.

These directions rest on two assumptions that are not presently met. First, research competencies able to tackle disabilities issues are needed on the two fields of applied and systematic research referring to the social model of disability. Presently, they are extremely limited as disabilities studies are not developed in academic curricula. This does not favour the generation of a research community on these issues. An effort has to be made in order to renew and to develop these competencies among social scientists.

Secondly, the participation of people with disabilities to the research process needs to be discussed seriously in the French academic and research context. At the best, parents of persons with disabilities are involved in research activities or agenda and claim to orientate the agenda on subjects of their interests in the name of disabled people. This is part of a benevolent conspiracy<sup>11</sup> that deprives disabled peoples from their own voice in the production of knowledge on their own lives. Research is a collective activity that needs to find ways to pay attention to disabilities issues and experience of disabled people. Insiders views on disabilities are needed to orientate research questions by taking support on experience-based expertise, to drive and to implement researches on disability. As in many other fields in social and public health research, participation of members of the community is a critical issue.

### **New fields for training and formation**

To promote and to renew a research community, disability issues and analysis must be integrated into higher education to gain visibility and to develop research and professional interests of students. As disabilities issues cross the economic and social sectors, the major tertiary curricula need to develop professional competencies to tackle discriminations and issues of social participation, as gender studies do in some sectors of higher education. Even if French curricula, which lean on academic disciplines (e. g. psychology, sociology) hardly favour intersectional approaches, the organisation of higher education offers real possibilities to introduce these issues and develop courses.

The 2005 law on disability opens a specific field of public intervention which requires professional specialized competencies. A central objective is to train professionals capable to implement institutional and structural conditions for the development of the citizenship and for the empowerment of disabled persons, and to be fully aware of ethical and human rights issues. This training needs to articulate the production of knowledge on the production of disabilities, and the conception of local regulations allowing disabled people to make their own choices.

Presently, higher education courses are mainly centred on the individual or medical model of disability. These trainings are important but they do not meet the issues of social participation and citizenship as they refer to an individual model of disability and to perspectives of adaptation of individuals to a normative environment. Training those professionals with reference to the social model of disability is needed.

In sum, the 2005 law offers opportunities in France to develop the social model of disability and to combine professional training, applied research and critical research on disability issues. These opportunities need a research community to be met. It is the academic challenge of coming years as regards disabilities studies.

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<sup>11</sup> To follow the expression coined by Edgerton to qualify such strategies of protection : Edgerton R.E., 1967, *The cloak of competence*, Berkeley, University of California Press.